General

Guideline Title

Fetal and perinatal autopsy in prenatally diagnosed fetal abnormalities with normal karyotype.

Bibliographic Source(s)

Desilets V, Oligny LL, Genetics Committee of the Society of Obstetricians and Gynaecologists of Canada, Family Physicians Advisory Committee, Medico-Legal Committee of the SOGC. Fetal and perinatal autopsy in prenatally diagnosed fetal abnormalities with normal karyotype. J Obstet Gynaecol Can. 2011 Oct;33(10):1047-57. [38 references] PubMed

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

The quality of evidence (I-III) and classification of recommendations (A-E, L) are defined at the end of the "Major Recommendations" field.

1. Standard autopsy should ideally be an essential part of fully investigating fetal loss, stillbirths, and neonatal deaths associated with non-chromosomal fetal malformations. (II-3A)
2. Clinicians and health care providers approaching parents for autopsy consent should discuss the options for a full, limited, or step-wise postmortem examination; the issue of retained fetal tissues; and the value of autopsy and the possibility that the information gained may not benefit them but may be of benefit to others. This information should be provided while respecting the personal and cultural values of the families. (III-A)
3. If parents are unwilling to give consent for a full autopsy, alternatives to full autopsy that provide additional clinical information must be presented in a manner that includes disclosure of limitations. (III-A)
4. External physical examination, medical photographs, and standard radiographic or computed tomography should be offered in all cases of fetal anomaly(ies) of non-chromosomal etiology. (II-2A)
5. Well-designed, large prospective studies are needed to evaluate the accuracy of postmortem magnetic resonance imaging. It cannot function as a substitute for standard full autopsy. (III-A)
6. The fetal and perinatal autopsies should be performed by trained perinatal or pediatric pathologists. (II-2A)
7. The need for additional sampling is guided by the results of previous prenatal and/or genetic investigations, as well as the type of anomalies identified in the fetus. Fibroblast cultures may allow future laboratory studies, particularly in the absence of previous karyotyping or if a biochemical disorder is suspected, and deoxyribonucleic acid (DNA) analysis. (II-3A)
8. In cases requiring special evaluation, the most responsible health care provider should have direct communication with the fetopathologist to

ensure that all necessary sampling is performed in a timely manner. (II-3A)

9. The most responsible health care providers must see the families in follow-up to share autopsy findings, plan for the management of future pregnancies, obtain consent for additional testing, and offer genetic counselling to other family members when appropriate. (III-A)

Definitions:

Quality of Evidence Assessment*

I: Evidence obtained from at least one properly randomized controlled trial

II-1: Evidence from well-designed controlled trials without randomization

II-2: Evidence from well-designed cohort (prospective or retrospective) or case-control studies, preferably from more than one center or research group

II-3: Evidence obtained from comparisons between times or places with or without the intervention. Dramatic results in uncontrolled experiments (such as the results of treatment with penicillin in the 1940s) could also be included in this category.

III: Opinions of respected authorities, based on clinical experience, descriptive studies, or reports of expert committees

Classification of Recommendations†

A. There is good evidence to recommend the clinical preventive action.

B. There is fair evidence to recommend the clinical preventive action.

C. The existing evidence is conflicting and does not allow to make a recommendation for or against use of the clinical preventive action; however, other factors may influence decision-making.

D. There is fair evidence to recommend against the clinical preventive action.

E. There is good evidence to recommend against the clinical preventive action.

L. There is insufficient evidence (in quantity or quality) to make a recommendation; however, other factors may influence decision-making.

*Adapted from The Evaluation of Evidence criteria described in the report of the Canadian Task Force on Preventive Health Care.

†Adapted from the Classification of Recommendations criteria described in the report of the Canadian Task Force on Preventive Health Care.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Fetal loss, stillbirths, and neonatal deaths associated with prenatally diagnosed non-chromosomal fetal anomalies

Guideline Category

Counseling

Diagnosis

Evaluation

Clinical Specialty

Family Practice

Medical Genetics

Obstetrics and Gynecology

Pathology

Pediatrics

Radiology

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Health Care Providers

Nurses

Patients

Physicians

Guideline Objective(s)

To review the information on fetal and perinatal autopsies, the process of obtaining consent, and the alternative information-gathering options following a prenatal diagnosis of non-chromosomal malformations, and to assist clinicians in providing postnatal counselling regarding fetal diagnosis and recurrence risks

Target Population

Women and families experiencing the loss of a fetus or newborn with prenatally identified non-chromosomal anomalies

Interventions and Practices Considered

1. Advising parents of the usefulness of autopsy in ascertaining the cause of fetal or perinatal death and for counselling them in their future pregnancies
2. Obtaining consent for a fetal or perinatal autopsy
3. Offering alternatives to full standard autopsy when families decline an autopsy, including magnetic resonance imaging (MRI), and discussing the limitations of these alternatives
4. External physical examination, medical photographs, and radiographic imaging
5. Performance of fetal or perinatal autopsy by trained perinatal, pediatric, or fetal pathologists following accepted protocols
6. Additional sampling if needed, including fibroblast cultures
7. Sharing autopsy findings with families, planning for the management of future pregnancies, and obtaining consent for additional testing
8. Offering genetic counselling to other family members when appropriate

Major Outcomes Considered

Accuracy (sensitivity and specificity) of conventional autopsy and magnetic resonance imaging in determining final cause of death or most clinically significant fetal abnormality

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Published literature was retrieved through searches of PubMed or Medline, CINAHL, and The Cochrane Library in 2009 and 2010, using appropriate key words (fetal autopsy, postmortem, autopsy, perinatal postmortem examination, autopsy protocol, postmortem magnetic resonance imaging, autopsy consent, tissue retention, autopsy evaluation). Results were restricted to systematic reviews, randomized controlled trials/controlled clinical trials, and observational studies. Additional publications were identified from the bibliographies of these articles. There were no date or language restrictions. Grey (unpublished) literature was identified through searching the websites of health technology assessment and health technology assessment-related agencies, clinical practice guideline collections, clinical trial registries, and national and international medical specialty societies.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality of Evidence Assessment*

I: Evidence obtained from at least one properly randomized controlled trial

II-1: Evidence from well-designed controlled trials without randomization

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II-3: Evidence obtained from comparisons between times or places with or without the intervention. Dramatic results in uncontrolled experiments (such as the results of treatment with penicillin in the 1940s) could also be included in this category.

III: Opinions of respected authorities, based on clinical experience, descriptive studies, or reports of expert committees

*Adapted from The Evaluation of Evidence criteria described in the report of the Canadian Task Force on Preventive Health Care.

Methods Used to Analyze the Evidence

Review of Published Meta-Analyses

Systematic Review

Description of the Methods Used to Analyze the Evidence

The quality of the evidence is rated using the criteria described by the Canadian Task Force on Preventive Health Care (see the "Rating Scheme for the Strength of the Evidence" field).

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Not stated

Rating Scheme for the Strength of the Recommendations

Classification of Recommendations†

A. There is good evidence to recommend the clinical preventive action.

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†Adapted from the Classification of Recommendations criteria described in the report of the Canadian Task Force on Preventive Health Care.

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

Internal Peer Review

Description of Method of Guideline Validation

This technical update has been prepared by the Genetics Committee of the Society of Obstetricians and Gynaecologists of Canada (SOGC), reviewed by the Family Physicians Advisory Committee and the Medico–Legal Committee of the SOGC and approved by the Executive of the SOGC.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Benefits of perinatal biopsy include:

- Explanations about cause of death
- More accurate genetic counselling to the family
- Help in planning for the management of future pregnancies
- Auditing of perinatal program outcomes
- Ensuring that families receive emotional support and bereavement care
- Enhancing teaching and medical knowledge

Potential Harms

Not stated

Qualifying Statements

Qualifying Statements

This document reflects emerging clinical and scientific advances on the date issued and is subject to change. The information should not be construed as dictating an exclusive course of treatment or procedure to be followed. Local institutions can dictate amendments to these opinions. They should be well documented if modified at the local level. None of these contents may be reproduced in any form without prior written permission of the Society of Obstetricians and Gynaecologists of Canada (SOGC).

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Implementation Tools

Chart Documentation/Checklists/Forms

Foreign Language Translations

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

Staying Healthy

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

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Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2011 Oct

Guideline Developer(s)

Society of Obstetricians and Gynaecologists of Canada - Medical Specialty Society

Source(s) of Funding

Society of Obstetricians and Gynaecologists of Canada

Guideline Committee

Genetics Committee

Composition of Group That Authored the Guideline

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Financial Disclosures/Conflicts of Interest

Disclosure statements have been received from all members of the committees.

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available in Portable Document Format (PDF) from the Society of Obstetricians and Gynaecologists of Canada (SOGC) Web site. Also available in French from the SOGC Web site.

Print copies: Available from the Society of Obstetricians and Gynaecologists of Canada, La société des obstétriciens et gynécologues du Canada (SOGC) 780 promenade Echo Drive Ottawa, ON K1S 5R7 (Canada); Phone: 1-800-561-2416.

Availability of Companion Documents

The appendix to the original guideline document contains a standardized approach to the perinatal autopsy, including a data collection sheet.

Patient Resources

None available

NGC Status

This NGC summary was completed by ECRI Institute on April 11, 2012. The information was verified by the guideline developer on May 10, 2012.

Copyright Statement

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